

Bonds of life—the Organ Transplant Law 20 yrs on / Boy’s words encouraged parents to make decision

8:55 pm, October 24, 2017

The Yomiuri Shimbun

Oct. 16 marked 20 years since the Organ Transplant Law came into effect. The law authorized organ donations from patients who are brain-dead. But even after all these years, there is a wide gap between the number of patients who need organs and the number of donors providing them. This is the first installment of a series that looks into issues related to organ transplants through interviews with people, including bereaved families of donors.

A mother, 39, clutched desperately at her son, who was lying on a hospital bed with a peaceful look on his face as if he were asleep. He was brain-dead, and then became one of a small number of child donors in Japan. His organs were on their way to places near and far to find new owners.

“His body is getting cold!”

She screamed, unable to contain herself, as she held his body against hers to warm it. He was a sixth-grader in elementary school. His body — which had just recently begun developing and getting bigger and stronger — was heavy, even with its organs removed.

“I’ll hold you tight, so your bucket of love won’t run empty.”

She repeated those words under her breath — something her family always says when they hug one another. Beside her, the boy’s father, 47, patted his son on the head and told him, “You did well, son.”

Their parting had been sudden. His mother had thought it odd that he was so quiet while taking a bath, and called to him from outside the bathroom. When he did not respond, she went in and found that he had sunk down in the bathtub. His heart was restarted, thanks to the first-aid measures administered by the emergency response team that rushed to the scene, but he did not regain consciousness.

Their son, who had a passion for judo, had been the very image of health. His parents never found out why he drowned.

A week after he was admitted to the hospital, the doctor showed his parents the chart of his brain activity. It had unmistakably flatlined.

“Is he brain-dead?”

They asked the question timidly, and the doctor nodded his head. A bleak reality was thrust in the faces of these parents, who had been hoping for a recovery.

He had been the life of his class at school, and always put a smile on people's faces. When a friend came to him with a problem, he always pondered it as if it were his own. If his mother became ill, he looked after his younger sister, even without his mother asking him to do so. He was not the best at judo, but he never missed a training session.

His dream was "to be a help to people." He loved watching TV documentaries, and was moved to tears watching clips of children who had gotten better after receiving organ transplants. He then talked about it with his family.

"If I ever become brain-dead and there's someone I can save, give them mine, OK?"

Because of that, his parents proposed donating his organs.

There were a total of 475 brain-dead organ donors as of September. It was only after a revision of the law in 2010 that children under 15 were able to become donors, but there have been only 15 such donors in the seven years since. There has been an endless stream of children going abroad to receive transplants.

It has been pointed out that one of the reasons why there are so few donors is the system in hospitals is not necessarily set up in a way that facilitates organ donations from willing patients.

Children, in particular, require a verification procedure to ensure that they have not been abused, and many hospitals are not used to administering it. This family's doctor went through the procedure with the manual in his hand every step of the way.

After the boy was confirmed as brain-dead, his family and two close friends walked him to the operating room, where his organs were removed.

His mother is still unable to accept her son's death, but the least she could do was grant his wishes.

"We're still sad every moment of every day. But it gives us hope knowing that the people who received his organs are in good health," the boy's mother said.

Bonds of life—the Organ Transplant Law 20 yrs on / Parents helped others by honoring son's wishes

4:30 am, October 26, 2017

The Yomiuri Shimbun

This is the second installment of a series.

“This precious torch of life has been passed on to me, and now I live as if I have been brought back from the dead.”

These words are from one of the several letters that Toru Hashimoto, 67, keeps at his home, letters that have been read over and over. Seventeen years ago, Toru's then 20-year-old son Koichi passed away. One of Koichi's kidneys was donated to the sender of the letters.

“Some people in Japan may have a negative view of organ transplants. But we are glad that we could donate.” Toru received the anonymous letters through the Japan Organ Transplant Network. In a way, they bear witness to the life that his son lived.

The topic of organ donation came up for them in May 2000. They were relaxing together at home when the death of Keizo Obuchi was announced on television. The death of this politician, who had recently been succeeded by Yoshiro Mori as prime minister after a sudden collapse from a stroke, led them to consider how fragile human life really is.

“If something happens to me, I think I'd like to donate my organs,” Toru said to Koichi, who was sitting beside him under a kotatsu table. Koichi had been diagnosed with a brain tumor four years earlier. He was always in and out of Yokohama General Hospital, which stood close to their home in Yokohama. While fighting the tumor, Koichi never spoke a word of complaint or unhappiness to his family. He was always cheerful. Surrounded by his friends, he even enjoyed his time in the hospital.

At one time, Toru had lived in the United States for work and had obtained a driver's license there. Even before Japan's Organ Transplant Law came into being in 1997, Toru had had the chance to declare his intention to be an organ donor when he received his U.S. driver's license. Back then, he did not hesitate to choose “Yes.”

“That's a good idea. I want to become a donor, too.”

That friendly reply, so typical of Koichi, always stayed with Toru.

Koichi's attending physician, Makoto Hiramoto, remembers words Koichi said out of the blue one day.

“I may die soon.”

“Nonsense. We’ll get through this together,” said Hiramoto, who was then head of the department of neurosurgery but is now the director of the hospital. Despite those encouraging words, Koichi may have realized what was to come.

Sometime later, after the last of many seizures, Koichi collapsed. In the summer of 2000, not long after his conversation with his father in May, Koichi was declared brain-dead. His parents were mentally prepared for their son’s death, so they must have been able to accept it quietly. But they cannot remember the moment they were told he was brain dead.

After that, however, Toru’s wife suddenly said, “Can we donate Koichi’s organs?” She explains what she was thinking: “I wanted to do it because it was what Koichi wanted. But to be honest, what I wanted the most was for my son to live on inside someone else.”

At that time, the Organ Transplant Law did not permit organs to be removed from someone who was brain dead without the written permission of that patient. The hospital also did not meet the conditions to carry out a transplant from a brain-dead donor. That is why only Koichi’s kidneys and corneas, the organs that could be removed without written permission after cardiac arrest, were donated to patients who needed them.

“Because we donated his organs, I feel like my son is still alive somewhere. I hope that organ transplants will become a normal part of medical care in Japan, the way they are in the United States,” Toru said.

In Japan, some people feel uneasy at the thought of damaging the body of a deceased person. Prejudice also remains against the idea of receiving the organs of someone else. Some say these conditions make it difficult for the bereaved families of organ donors, patients who receive organs and patients on waiting lists to speak out.

Still, Toru decided to reveal his name and face as he told Koichi’s story. Surely, Koichi would have been happy for his father to do so.

Bonds of life—the Organ Transplant Law 20 yrs on / Hope springs from sudden opportunity for new liver

7:34 pm, October 26, 2017

The Yomiuri Shimbun

This is the third installment of a series.

It was before dawn when Shota Inoue was shaken awake by his father, who had received a phone call from his doctor.

“We have a donor. But it’s been a long time since the liver was extracted, so it’s risky.”

Five years ago in autumn — before 5 a.m. even — the 22-year-old listened to the doctor’s strained voice over the phone at his home in Setagaya Ward, Tokyo.

Inoue was born with an incurable metabolic disorder. Due to the illness, his liver could not detoxify ammonia. The illness is not one to worsen suddenly.

However, when ammonia builds up in the blood, it can cause vomiting, convulsion and loss of consciousness — and even threaten one’s life.

He had been getting by on a strict low-protein diet, but in high school he often suffered attacks from his illness. A liver transplant would be the only cure.

He often felt like “his turn for a transplant would never come” because there are not a large number of donors in Japan.

The doctor on the phone was Mureo Kasahara, who is in charge of organ transplants at the National Center for Child Health and Development near Inoue’s home. But Kasahara was in Morioka at the time.

The previous night, a patient at Iwate Medical University Hospital was to receive a liver transplant from a donor in the Tokai region. Kasahara was asked to assist and went to the donor’s hospital to extract the liver. They took the liver to Iwate by air, but the patient’s condition suddenly changed, and the transplant could not be done.

When a donor appears, the Japan Organ Transplant Network confirms whether each patient on the waiting list for each organ wants to receive the transplant. They also take into account the severity of their conditions and other factors.

In this case, the scheduled transplant was canceled and the patient selection process had to start again after midnight.

There were many patients ahead of Inoue on the list. But the donor's liver was healthy and clean, and the blood type matched his. "Sho-chan might have a chance," Kasahara thought.

Liver transplants from brain-dead donors are said to be allowable within 12 hours of the organ's extraction. However, around four hours had already passed. Would the liver last until the surgery?

Working under limited time, more than 30 patients were rejected. Inoue came up next — the 37th patient on the list.

Inoue ended the call with Kasahara and told his parents.

It is said that even if a liver is transplanted, there is a 20 percent to 30 percent chance of it not working.

His father, 47, said to his concerned mother, 48: "He's not a child anymore. Let's respect his decision."

Inoue called Kasahara back. The doctor's voice was tense.

"Sho-chan, if I don't get on the first Shinkansen train, I won't make it." The sound of an ambulance siren could be heard in the background.

"Okay. I'll take the liver."

Kasahara and his colleagues got into the ambulance and rushed to a train station. The Shinkansen train was full, so they had to stand. The cold box with the liver inside weighed at least 20 kilograms. The strap ate into the doctor's shoulder.

They arrived at the center after 9:30 in the morning. In the operating room, Inoue's attending physician, Akinari Fukuda, was waiting with his colleagues around an already anesthetized Inoue.

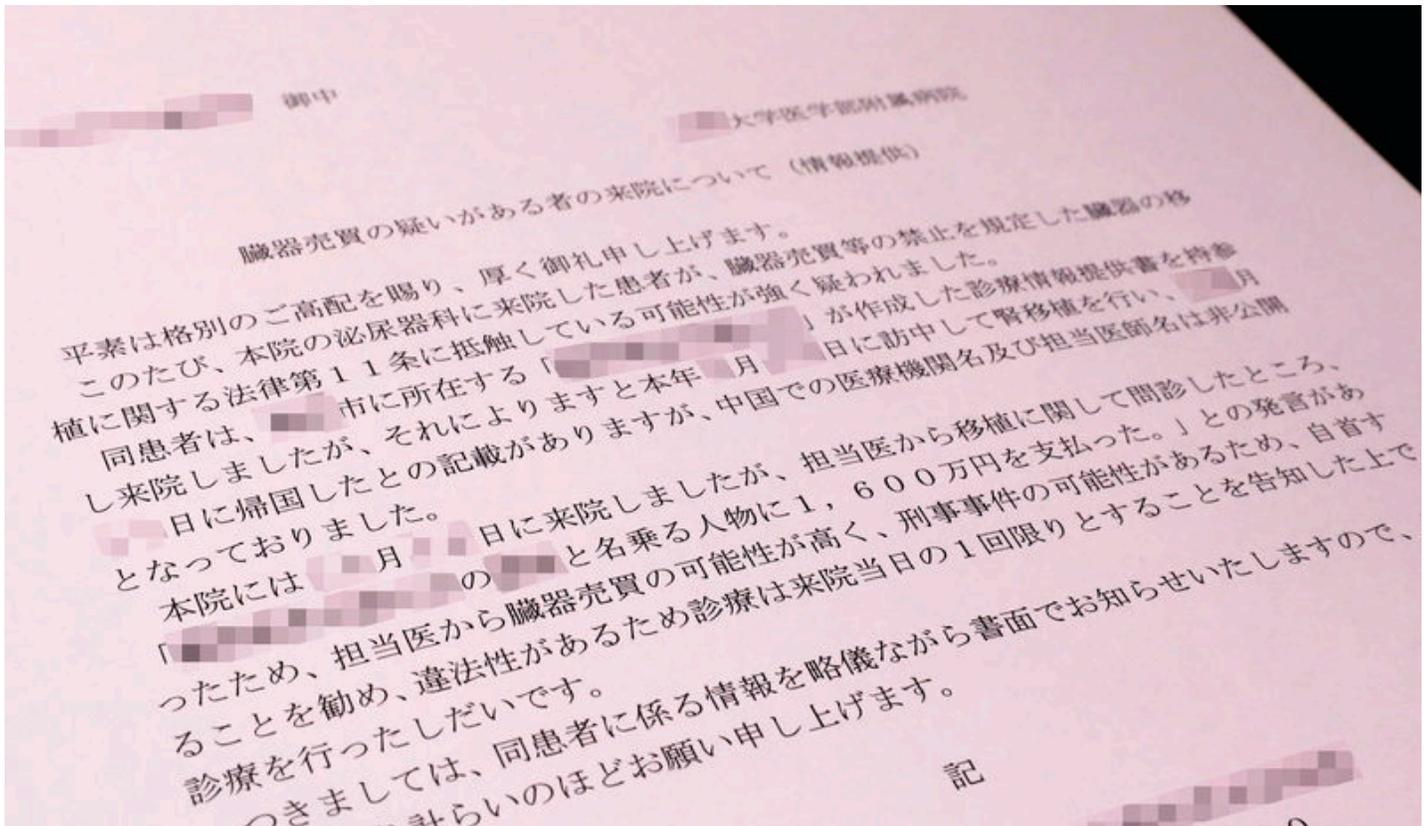
The transplant was successful. Inoue overcame the postoperative complications and was discharged from the hospital about two months later. He has made a steady recovery, and is now attending university and throwing himself into skiing. He is really happy to be able to eat anything he wants.

"My world has changed," he said sincerely.

Fukuda commented on the bitter reality: "Opportunities for transplants in Japan are extremely rare. So we have to force our patients into making difficult decisions," he said.

If they miss an opportunity, there most likely will not be another.

Bonds of life—the Organ Transplant Law 20 yrs on / Traveling overseas in dire quest for donor can lead to pitfalls back home



The Yomiuri Shimbun

A document submitted to police by a national university hospital in the Kansai region reports on a patient who had received an organ transplant in China. (The image has been partially modified.)

8:00 pm, October 27, 2017

The Yomiuri Shimbun

This is the fourth installment of a series.

“You’ll need to be put on dialysis within a year.”

A 67-year-old man living in Shizuoka Prefecture was told this by his family doctor in 2014. He was suffering from chronic kidney failure due to an intractable disease.

The man was apprehensive about a life of visiting a hospital for dialysis three times a week, with each session taking about four hours. An organ transplant was the only treatment for his kidney failure, but there are few donors in Japan, making the average waiting period nearly 15 years. The man became desperate and finally turned to the internet.

He found the website of a nonprofit organization that helped people get organ transplants overseas. He later visited the NPO's office, where a staff member told him, "Let's go to China."

The total cost of the trip, including surgery and accommodations, was about ¥17 million. In December 2014, the man traveled to China with a member of the NPO's staff. He stayed at a hotel for 40 days waiting for a donor and eventually received a transplant in January 2015 at a large hospital in Tianjin that was said to have experience with such surgeries.

After returning home, the man visited Hamamatsu University Hospital to check on his progress, but the hospital refused to see him. The hospital said its staff had a consensus not to see organ transplant patients who had received a kidney that might be involved with trafficking.

The Organ Transplant Law prohibits organ trafficking, and people who travel overseas for transplants are viewed with a harsh eye around the world. All countries face an insufficient number of donors compared to the number of people who need transplants.

Criticism is intensifying against transplant tourism, in which people from developed countries travel to mainly developing countries to pay for organ transplants. The Transplantation Society in 2008 adopted the Declaration of Istanbul, which calls for each country to save its own patients. In 2010, the World Health Organization issued new guidelines including similar policies to the declaration.

Traveling abroad for transplants has since become difficult. There are said to be a few exceptions, such as official acceptance of child patients for heart transplants in the United States.

The man said he is treated at a Tokyo hospital that accepts him and his condition is stable. However, he could not accept the university hospital's refusal to see him and filed a lawsuit against it in July 2015.

"I only paid the necessary expenses to the NPO. I've never thought that I bought an organ," he said. The university declined to comment.

The NPO said, "As long as there are patients who need transplants and a way to get them, we'll continue to do what we can."

Through what means does the NPO obtain the cooperation of hospitals and doctors in China and how does it find donors? The Yomiuri Shimbun asked the NPO for more detailed information on these points, but the organization only said it would answer at a later time. As of Oct. 18, the NPO had yet to reply.

Other hospitals in Japan have also been visited by patients who received organ transplants overseas.

A national university hospital in the Kansai region saw such a patient five years ago. It asked the person to report to the police, telling the patient that there may have been a violation of the Organ Transplant Law.

According to the hospital's internal documents, it later reported the case to the nearest police station.

A urologist at a private university hospital in Tokyo said, "A patient came to us after getting an organ transplant in China with the help of an unknown organization."

More than 12,000 patients registered with the Japan Organ Transplant Network are waiting for a kidney transplant. Yet there were only 96 donors who were brain dead or in cardiac arrest in 2016.

The number of organizations that arrange for organ transplants overseas independently, without going through domestic medical institutions, is said to have decreased. However, there are still several such organizations online. Faced with a shortage of donors, patients come knocking on their doors.

Even the Health, Labor and Welfare Ministry and academic societies are unsure just how many patients are traveling overseas for organ transplants.

Bonds of life—the Organ Transplant Law 20 yrs on / Gradual steps toward acceptance

12:00 am, October 29, 2017

The Yomiuri Shimbun

This is the fifth and final installment of a series.

“I know this is sudden, but would you consider donating your son’s organs?”

The parents were speechless upon hearing the doctor say this. They faced him, dumbfounded, as tears rolled down their cheeks.

This is a scene from the bestselling French novel turned hit movie “Heal the Living,” in which a 17-year-old boy suffers brain death as a result of a car accident while on his way home from a surfing trip.

His parents eventually decide to donate his organs. A woman with heart disease is given the opportunity to have a transplant, but is also conflicted.

“Humans have a life span. To use someone else’s heart ...”

On Sept. 16 in Shibuya Ward, Tokyo, the opening day of the movie, people waiting for a transplant and people who have had transplants gathered at a cinema. They were invited by Satoru Ishii from Higashiyamato, Tokyo. The 35-year-old suffers from dilated cardiomyopathy and is using an artificial heart as he awaits a transplant.

In France, where the movie is set, the number of organ donations per 1 million people was 27.5 in 2015. But in Japan, it was 0.7. The fewer donors in Japan compared with Western countries is not just because of systemic differences, but also because of Japan’s unique spiritual culture.

However, people in the movie have similar emotional reactions to Japanese — in the depths of their sadness, the boy’s parents are conflicted about donating their son’s organs. The would-be receiver wants to be helped, but at the same time feels guilty about prolonging her own life with another person’s organ.

Ishii gave his thoughts on the movie: “The countries, systems and cultures are different, but the human emotions are the same. I hope organ transplants will someday become a normal medical treatment in Japan as well.” Other people who gathered to see the movie were also caught between impatience and conflict.

Change on the horizon?

At the end of 2016, 556 people were waiting for a heart transplant in Japan. Developments in artificial hearts mean people can wait longer for a heart transplant, and the list grows by about 100 people every

year. But there are only about 60 cases of brain death per year that result in organ donations — a vast difference.

There is worldwide disapproval of traveling abroad to receive transplants, but there is still no end to the number of people who have gone overseas because they don't feel like they have enough time to wait for a transplant.

Looking at the domestic situation, the hospital system is unprepared — meaning families that want to donate organs are unable to.

The Japan Organ Transplant Network, which facilitates organ donations, has also made several errors in selecting who will receive donations. It is said the network faces a shortage of well-trained coordinators to explain its decisions to families.

Even so, there has recently been some good news. In the more than 10 years since the Organ Transplant Law went into force in 1997, the number of brain-dead donors has continued to grow from what used to be in the single digits per year. A turning point was the revision of the law in 2010 allowing for donations to be offered simply with family consent.

A national survey showed that nearly half of people have positive feelings toward donation. A change can be seen in the younger generation, which is increasingly in favor of it.

The Organ Transplant Law, now in its 20th year, contains this basic ideal in its second article: “The intention of the deceased that his or her organs should be donated to be used in transplant surgery, which he or she had while alive, must be respected.”

The wishes of the donor and the family should be connected as much as possible with those who cannot be helped except through transplants. These issues will be passed on in the future.

This series was written by Yomiuri Shimbun Staff Writers Yukiko Takanashi and Nozomi Suzuki.